



Patient and Public Partnership Strategy 2019-2023





Contents

Foreword	2
Executive summary	4
1. Key statistics	7
2. Strategic context	8
International	8
National	8
Organisational	9
What is Patient and Public Partnership?	10
How has this strategy developed?	13
3. Vision and Mission	14
4. Principles	15
5. Strategic Areas	16
Strategic area 1: Empower patients and the public to play an active role in NSS	17
Strategic area 2: Embed partnership working across the NSS	19
Strategic area 3: Strengthen accountability, assurance and learning	21
Appendices	23
Appendix 1: Workshop Participants	23
Appendix 2: Theory of Change for NSS Patient and Public Partnership Strategy	25
Appendix 3: NSS Patient and Public Partnership Action Plan	26
Glossary	33
Definitions	33

Foreword

Patient Panel Representatives

As patient representatives involved with National Screening Service (NSS), with backgrounds in voluntary cancer service, hospital patient advocacy and patient committees, we along with staff of the NSS are proud to be involved in this strategy. We are committed to using our collective skills and experiences to develop and deliver a world class screening service for all. We aim to achieve a cultural shift using patient representatives to identify where and how to improve our services, resulting in a better outcome for all our service users.

We aspire also to develop a service where staff feel appreciated, sufficiently trained and supported, leading to a compassionate patient-centric service that delivers positive patient experiences and high quality care. We want to be inclusive of all social, economic and geographical groups. We aim to educate the general population about our screening services and to actively engage where there are patient concerns.

We look forward to a successful implementation of the strategy through meaningful engagement, listening, learning and ongoing reviews throughout. We are aiming high together to benefit all stakeholders.

Breda, Mary and Grace
Patient Representatives



Dr Caroline Mason-Mohan, Director of Public Health, NSS

As the Director of Public Health, I am honoured to be a part of developing the first NSS Patient and Public Partnership (PPP) strategy and I am committed to delivering the objectives we have set.

Screening programmes aim to improve the health of the population. To get the most from our screening programmes we need to make sure that they are based on sound evidence and that we deliver them to a high standard.

We also need to make sure everyone who is eligible for services has a chance to have the screening they are entitled to.

That means we need to understand what it feels like for you to use our services and what gets in the way of you using them.

It means giving you information in a way that is understandable to you, that explains the benefits and any potential harms of your screening so that you can make the right choice for you.

It means making you feel welcome in our services and making our services accessible to you, regardless of your age, gender, disability, ethnic identity or sexual orientation.

The Scally report¹ provided us with many recommendations to improve screening services and we have been making those changes. The key things that Scally taught us are to listen to the stories of the people who use our services and that we must deliver services with grace and compassion. We know that working in partnership with patients and the public delivers better health outcomes and we believe that by partnering with patients and the public we can ensure the learning from what went wrong is properly embedded in NSS.

The NSS Patient and Public Partnership strategy gives us the opportunity to work with patients and the public across our services to understand your needs better, have you inform the changes and to do that as part of the way we do our business. This will benefit us all.

1 <http://scallyreview.ie/wp-content/uploads/2018/09/Scoping-Inquiry-into-CervicalCheck-Final-Report.pdf>

Executive Summary

Partnering with patients and the public is to share decision making power and ensure they can influence decisions on the design, delivery and evaluation of services. Partnering with patients is central to delivering person-centred care; which refers to “services that are respectful and responsive to individual’s needs and values and partners in designing and delivering that care”.²

We are committed to patient and public partnership in the National Screening Service because:

- Patient and public partnership involvement in healthcare delivery is an ethical right.
- Patient and public partnership builds trust between the patient and the healthcare services, it enhances communication and transparency. Patient and public partnership leads to improvements in health outcomes.³

This is the first National Screening Service Patient and Public Partnership strategy and it sets out how we will achieve the objective of strengthened patient and public partnership in the NSS over the next four years. The project was established in response to the loss of public confidence in the cervical screening programme and to learning from the Scoping Inquiry into the CervicalCheck Screening Programme by Dr Gabriel Scally, September 2018. It also builds on the patient involvement work initiated by the NSS previously.

A key learning point from Scally is to listen to the voices of the women affected and ensure services are delivered with grace and compassion. Having patients at the centre of decision making will help ensure our services are meeting the needs of users and are delivered through our HSE values: Care, Compassion, Trust and Learning.

2 Health Service Executive (HSE) Quality Improvement Framework <https://www.hse.ie/eng/about/who/qid/framework-for-quality-improvement/>

3 England, S., and Evans, J., 1992. Patients’ choices and perceptions after an invitation to participation in treatment decisions. *Social Science Medicine*. 34:1217-1225

Fallowfield, L., Hall, A., Maguire, G., and Baum, M., 1990. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *British Medical Journal*. 301: 575-580.

Chambers, R., and Drinkwater, C., and Boath E., 2003. *Involving Patients and the Public, How to do it Better*. Radcliffe Medical Press.

This strategy also takes into account the recommendations in the MacCraith⁴ review to ensure there is a culture of 'Women First', and although "person-centred" is the terminology used throughout, the concept of Women First is at the forefront. We will consider this in more depth at a co-production workshop with staff and patients, to be led by an international expert in patient partnership. The action plan document will then be updated accordingly. This is a 'living' document and will be reviewed and updated at regular intervals.

The development of the strategy has been led by a project team consisting of three patient panel representatives; NSS staff from the Quality and Safety, Health Promotion and Project Management Office; and the HSE Quality Improvement Team.

The content of the strategy has been co-developed over two workshops held with approximately 40 staff and public representatives. The first workshop aimed to bring staff and patient representatives together to develop a shared vision statement, set out the principles underpinning the strategy, and outline the high level strategic work areas.

The second workshop involved action planning, where the strategic work areas were confirmed, and more detailed actions supporting each of these were co-developed as a group.



4 <https://www.hse.ie/eng/services/publications/corporate/independent-rapid-review-of-specific-issues-in-the-cervicalcheck-screening-programme.pdf>

Our strategic work areas are:



Actions

Strategic area 1: Empower patients and the public to play an active role in NSS

Work in equal partnership with patients and the public, mutually supporting each other to achieve shared decision making.

- Establish an effective, diverse and representative PPP panel through regular open recruitment ensuring representation from marginalised groups.
- Improve screening health literacy of the public and staff.

Strategic area 2: Embed partnership working across the NSS

Create a culture of 'person-centeredness' and partnership working at every level of the organisation.

- Ensure strong leadership and buy-in.
- Culture change: develop awareness and understanding of partnership working across NSS.
- Establish a PPP Hub.
- Establish ways of working for PPP.

Strategic area 3: Strengthen accountability, assurance and learning

Ensure there is social accountability for NSS services and that participation and monitoring leads to learning and improvement.

- Ensure clear governance and accountability structures for PPP.
- Measure success of PPP.

1 Key statistics

The National Screening Service currently has four national programmes – BowelScreen, BreastCheck, CervicalCheck and Diabetic RetinaScreen. Each programme operates countrywide offering free screening to those eligible in various locations.

Screening services differ from other health services as they invite seemingly healthy people with no overt symptoms to assess their risk of having a particular pre-condition. The aim is to reduce the severity of disease by diagnosing it at an earlier stage where treatment outcomes might be better.

BowelScreen

- BowelScreen was introduced in 2012 with a phased implementation plan. It was initially offered to people aged 60-69 every three years, changing to every two years in 2016. The total eligible population is approximately 0.5m.
- Between 2012 and 2015, there were 196,238 participants in BowelScreen, 8,062 colonoscopies conducted, and 521 cancers detected.

BreastCheck

- Breastcheck offers all women between the ages of 50 and 67 a breast cancer test (a mammogram) every two years. By 2021, the service will be available to women aged 50-69.
- As of 2017, BreastCheck has provided over 1.7m mammograms to over 540,000 women and has detected over 11,000 cancers. There is a cancer detection rate of 6.5 per 1,000 women screened (2017 report)

CervicalCheck

- Approximately 1.1 million women are eligible for cervical screening. It is offered to women aged 25-60 years.
- In the first nine years of CervicalCheck, the programme has detected 1,400 cancers, 57,805 cases of high grade cervical abnormalities and 43,883 cases of low grade abnormalities.

Diabetic RetinaScreen

- Diabetic RetinaScreen (commenced in 2013) offers diabetic retinopathy screening to all people aged 12 years and older with a diagnosis of type 1 or 2 diabetes.
- Between 2013 and 2015, 147,929 people were invited for diabetic retinopathy screening. Of these, 67% had no retinopathy, one quarter was found to have background retinopathy, and a small number were found to have pre-proliferative and proliferative retinopathy. Non-diabetic eye disease was also detected and referred to ophthalmology services.

2 Strategic Context

International

World Health Organization's Health 2020

Health 2020⁵ is the European health policy framework. It aims to support action across government and society to: “significantly improve the health and well-being of populations, reduce health inequalities, strengthen public health and ensure people-centred health systems that are universal, equitable, sustainable and of high quality”.

The two strategic objectives are:

- improving health for all and reducing health inequalities
- improving leadership and participatory governance for health.

National

Healthy Ireland 2013 – 2025⁶

Healthy Ireland is the national framework for action to improve the health and wellbeing of the people of Ireland. Its main focus is on prevention and keeping people healthier for longer. Healthy Ireland's goals are to:

- increase the proportion of people who are healthy at all stages of life
- reduce health inequalities
- protect the public from threats to health and wellbeing
- create an environment where every individual and sector of society can play their part in achieving a healthy Ireland

Healthy Ireland takes a whole-of-Government and whole-of-society approach to improving health and wellbeing and the quality of people's lives.

Sláintecare⁷

The Sláintecare Implementation Strategy is the government's plan for delivering a sustainable and equitable health and social care service over the next 10 years. It is the roadmap for building a world-class health service for the Irish people. Engagement is a key pillar of the implementation strategy, it puts the public voice at the heart of the reform process and commits to empowering people to look after their own health and to holding the health service to account.

5 http://www.euro.who.int/_data/assets/pdf_file/0011/199532/Health2020-Long.pdf?ua=1

6 <https://health.gov.ie/healthy-ireland/>

7 <https://assets.gov.ie/22607/31c6f981a4b847219d3d6615fc3e4163.pdf>

Public Sector Equality and Human Rights Duty⁸

Public sector organisations are bound by the Public Sector Equality and Human Rights Duty which places responsibility on organisations to: eliminate discrimination; promote equality of opportunity and treatment of its staff and persons to whom it provides services; and protect human rights of its members, staff and the persons to whom it provides services.

Scoping Inquiry into the CervicalCheck Screening Programme by Dr Gabriel Scally, September 2018

The report published in response to the CervicalCheck controversy made 50 recommendations to the Department of Health, HSE, NCRI and NSS to strengthen governance, quality assurance and performance management processes. A central theme of the report was listening to the voices of the women affected and demonstrating grace and compassion. The NSS are currently implementing all recommendations in the report.

Organisational

Independent Rapid Review of Specific Issues in the CervicalCheck Screening Programme by Brian MacCraith, August 2019

The report was published in response to an incident in the CervicalCheck screening programme where results were not issued to women and they were not informed of the reasons for the delay. A key recommendation in the report is adopting a Women First approach focusing on the continuous flow of information, customer relationship and trust building measures.

HSE National Services Plan 2019⁹

Developing a patient engagement plan was one of the NSS priorities in the 2019 services plan.

The National Healthcare Charter: You and Your Health Service (2012)

The charter was developed by a diverse group of people with a common goal and aims to inform and empower people to actively look after their own health and to influence the quality of healthcare in Ireland.

8 <https://www.ihrec.ie/our-work/public-sector-duty/>

9 <https://www.hse.ie/eng/services/publications/serviceplans/national-service-plan-2019.pdf>

HSE Quality Improvement Framework 2016¹⁰

The framework provides a strategic approach to improving quality whether at the front-line, management, board or national level. It is oriented towards quality and safety and to improve patient experience and outcomes. Person and family engagement is a core pillar of the framework and states that engaging and involving patients in the design, planning and delivery of all care demonstrates a commitment to person-centred care.

HSE National Intercultural Health Strategy 2018-2023

In January 2019, the HSE published the Second National Intercultural Health Strategy 2018-2023.¹¹ This document commits to five goals, which are aligned to the HSE's corporate strategy and its legislative obligations:

1. Enhance accessibility of services to service users from diverse ethnic, cultural and religious backgrounds.
2. Address health issues experienced by service users from diverse ethnic, cultural and religious backgrounds.
3. Ensure provision of high-quality, culturally responsive services to service users from diverse ethnic, cultural and religious backgrounds.
4. Build an evidence base.
5. Strengthen partnership working to enhance intercultural health.

What is Patient and Public Partnership?

Patient involvement is “a critical part of a continuously learning health system”¹², and is frequently advocated for as best practice. It is an essential part of delivering healthcare, with a number of countries opting to enshrine the duty to involve patients in the design, delivery and evaluation of services in legislation (e.g. NHS constitution).

Chambers (2017)¹³ states we are living in a rapidly changing world with a more informed population that has greater expectations of healthcare services. As healthcare is an ever-changing field this results in a constant transformation within the dynamics of the doctor-patient relationship, which is more notable as we move away from the traditional “paternalistic approach to one of partnership working and shared decision-making”.

Arnstein's (1961) Ladder of Citizen Participation is a widely accepted model and adaptations of it are still frequently used in healthcare (see Figure 1). The model describes eight levels of participation, ranging from non-participation (no power), to shifting decision making power completely to citizens. The middle rungs are “informing, consulting and placating”, which represent different levels of participation and can be used appropriately in different circumstances but have sometimes been criticised for being tokenistic if they are the only means used.

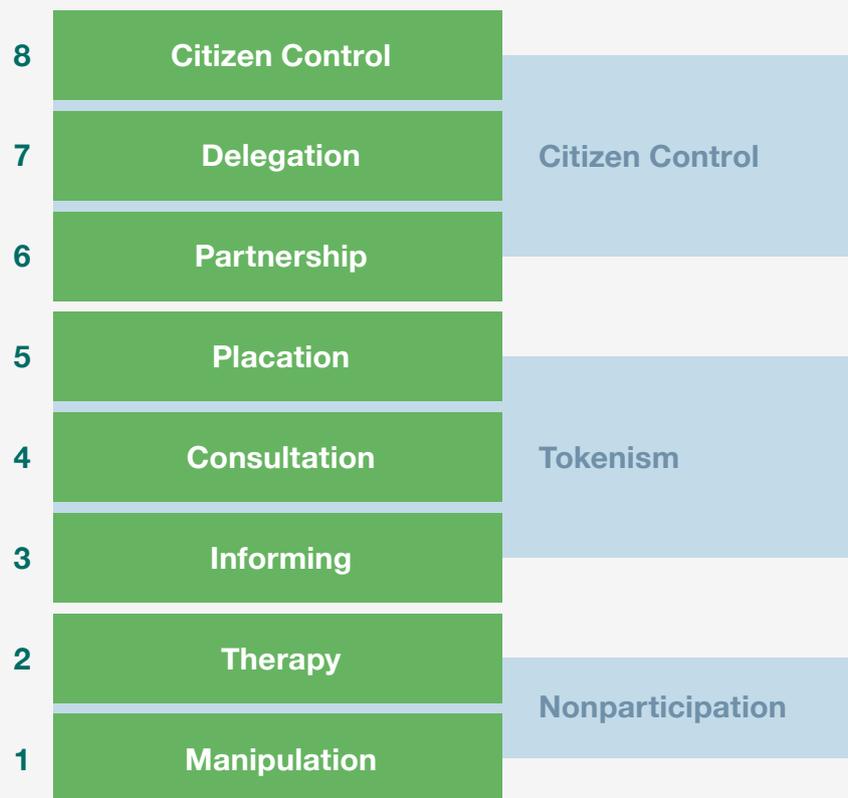
10 <https://www.hse.ie/eng/about/who/qid/framework-for-quality-improvement/framework-for-improving-quality-2016.pdf>

11 <https://www.hse.ie/eng/about/who/primarycare/socialinclusion/intercultural-health/intercultural-health-strategy.pdf>

12 ‘Patients Charting the Course: Citizen Engagement and the Learning Health System’: Workshop Summary. Ed by Institute of Medicine, The National Academies Press, Washington, DC, 2011.

13 <https://onlinelibrary.wiley.com/doi/10.1111/hex.12550>

Figure 1: Arnstein's Ladder of Citizen Participation



Arnstein's Ladder (1969)

Degrees of Citizen Participation

Source: The Citizen's Handbook¹⁴

The NSS wishes to move to a partnership approach where decision making is shared between patient and public representatives and staff, although other mechanisms of involvement may be used for specific tasks as required. There are also Irish documents that outline different types of involvement and the situations when they should be used¹⁵.

Partnering with patients is central to delivering person-centred care, which is the central aim of the HSE Framework for Improving Quality (see Figure 2). The WHO states that "people-centred care is the embodiment of human rights in the practice of care", and the HSE refers to person-centred care as services that are "respectful and responsive to individual's needs and values and partners with them in designing and delivering that care" (HSE Quality Improvement Framework). Partnering with patients and the public in decision-making demonstrates commitment to person-centred care.

14 <http://www.citizenshandbook.org/arnsteinsladder.html>

15 https://health.gov.ie/wp-content/uploads/2018/03/Final-WEB-COPY_PI-Framework-Feb-2018-1.pdf

Figure 2: HSE Framework for Improving Quality



The NSS has made significant progress in including the patient and public voice on key decision making boards and steering groups over the last year. Currently there are patient representatives on six committees, including the Quality, Safety and Risk Committee, and the expert reference groups tasked with developing clinical audit and open disclosure functions in the NSS. Having the patient voice included in these key governance groups has been very successful and the aim is to build on this and embed across the organisation.

There will also be two patient representatives on the new National Screening Committee – an independent body tasked with assessing evidence for and implications of introducing new screening programmes or modifying existing ones.

A key factor of strong partnership working is recognising and valuing the expert experiential knowledge that service users bring with them and incorporating their views to improve services.

Why is Patient and Public Partnership important?

- Patient and public partnership involvement in healthcare delivery is an ethical right.
- Patient and public partnership builds trust between the patient and the healthcare services, it enhances communication and transparency.
- Patient and public partnership leads to improvements in health outcomes (England et al 1992, Fallowfield 1990, Chambers, 2003).

How has this strategy developed?

In late 2018, a project team was convened to oversee the development of the patient and public partnership strategy for NSS. The team was made up of NSS staff from Quality and Safety, Health Promotion and Project Management Office; HSE Quality Improvement Team; and three patient panel representatives. There were two strands to this work: 1) Recruiting to an NSS patient panel and 2) Co-developing a four year Patient and Public Partnership strategy.

A short literature review was conducted in February 2019 to review recent and emerging evidence on successfully partnering with patients in population health services. The review included assessing the barriers and enablers to successful engagement. Staff and patient panel representatives were also surveyed to assess their knowledge, commitment and attitudes to patient and public partnership working.

It was decided that a co-design approach should be employed to develop the strategy, resulting in two co-design workshops being hosted in May and June 2019, both facilitated by a neutral external consultant. The first workshop aimed to bring staff and patient representatives together to develop a shared vision statement, set out the principles underpinning the strategy and to outline the high level strategic work areas. The second workshop was an action planning workshop where the strategic work areas were confirmed and more detailed actions supporting each of these co-developed as a group. A list of participants who attended the workshops can be found in Appendix 1.

The outputs from the workshops were used to develop the overarching theory of change (see Appendix 2) and create a supporting action plan (Appendix 3). A two-week consultation was held with the staff and public representatives who attended the workshop.

3 Vision and Mission

HSE Vision

A healthier Ireland with a high quality health service valued by all

Patient and Public Partnership Mission

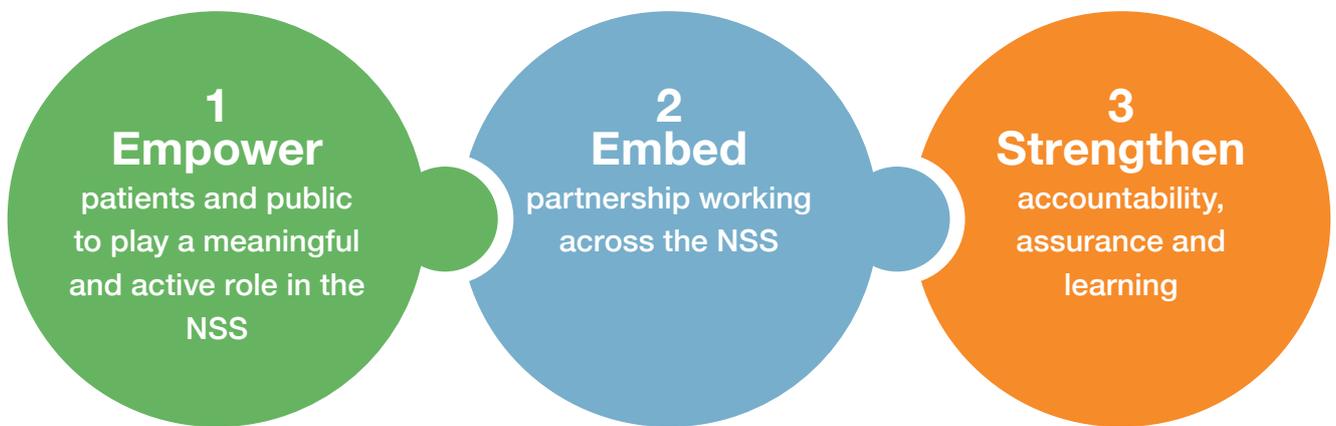
To improve health outcomes through inclusive, high-quality, person-centred screening services where the voices of participants are included in decision-making

4 Principles

Figure 3:



5 Strategic Areas



Strategic area 1: Empower patients and the public to play an active role in NSS

Work in equal partnership with patients and the public, mutually supporting each other to achieve shared decision making.

There is an imbalance of power when people who have lived experience are reliant on a system where the organisation holds the decision-making power.

To move to a power-sharing and shared decision-making framework, it is important to build trust and form reciprocal relationships. A fundamental part of doing this is to address barriers to involvement and redress the balance of power through improving access to information, being open and transparent, actively listening, and taking care that empowerment approaches do not exacerbate or reinforce health inequity.

A crucial component is to provide training and development opportunities to support people to play active roles. We must recognise that participants are experts by experience. We must provide support to ensure they have the necessary skills, confidence, and knowledge of the relevant policies and systems to be able to play active roles.

Figure 4: Investments needed to empower people



Source: Centre for Empowering Patients and Communities (CEmPaC) (2019)

Summary of actions:

- **Establish an effective, diverse and representative PPP panel:**

- Develop targeted recruitment campaign.
- Develop a PPP toolkit (e.g. mapping expectations; checklists; 'how to' guides).
- Establish ways of working.
- Run induction and orientation sessions.
- Training for representatives.
- Review digital methods of engagement.
- Co-develop shared decision-making framework.

- **Improve screening health literacy of the public and staff**

- Use plain English and remove jargon.
- Conduct literacy checks on communications materials with patient reps.
- PPP input to mass media campaigns.
- Link with training institutions to increase screening knowledge amongst healthcare staff.



Strategic area 2: Embed partnership working across the NSS

Create a culture of person-centeredness and partnership working at every level of the organisation.

There are many benefits to partnering with patients and the public to improve the design, delivery, quality and safety of services and also in improving staff morale.

Looking at services through a patient lens helps staff meet the needs of users. It gives staff a direct line of sight to the patient regardless of whether their roles or functions are frontline, managerial, or national. Embedding a culture of person-centeredness must be supported by senior management, but all staff must be empowered in order to successfully deliver it.

The barriers to successful partnership working must be understood and addressed to ensure it is meaningful. At the organisational level, factors that can hinder partnership working in service planning and decision-making include representatives feeling unclear about their role and what is expected of them, a shortage of resources to support the process, concerns about representation, and occasional resistance from healthcare staff¹⁶.

Recent research suggests that interpersonal elements of engagement also require attention in terms of roles and boundaries and how they relate together but also in terms of the wider culture¹⁷. There are a number of tools and resources available to support patient and public involvement which we will seek permission to use and adapt to guide our work. A toolkit for staff linking behaviours to values will also be developed to facilitate widespread adoption across the organisation.

Figure 5: Patient and Public Partnership Input to NSS services



16 Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Quality & Safety* 2016;25:626-632.

17 Devonport, T.J., et al. (2018). "It's not just 'What' you do, it's also the 'Way' that you do it: Patient and Public Involvement in the development of health research." *International Journal for Quality in Health Care* 30(2): 152 -156.

Summary of actions:

- **Ensure strong leadership and buy-in**

- Have named senior responsible officers for patient and public partnership.
- Provide regular updates to senior management team meetings.

- **Culture change: develop awareness and understanding of partnership working across NSS**

- Create awareness through using Values in Action model to develop NSS workplace behaviours based on person-centeredness and partnership working values.
- Develop posters and aids showing how partnership working and person-centeredness can be translated into everyday behaviours and actions.

- **Establish a PPP Hub**

- Establish steering group / Hub for PPP.
- Establish working groups of staff and patients for each of the PPP strategic areas (co-production groups).
- Hold regular coproduction workshops with staff and patient and public representatives.
- Training for staff on PPP.

- **Establish ways of working for PPP**

- Incorporate PPP into NSS policies and processes.
- Define committees where PPP input required.
- Add PPP as standing agenda item.



Strategic area 3: Strengthen accountability, assurance and learning

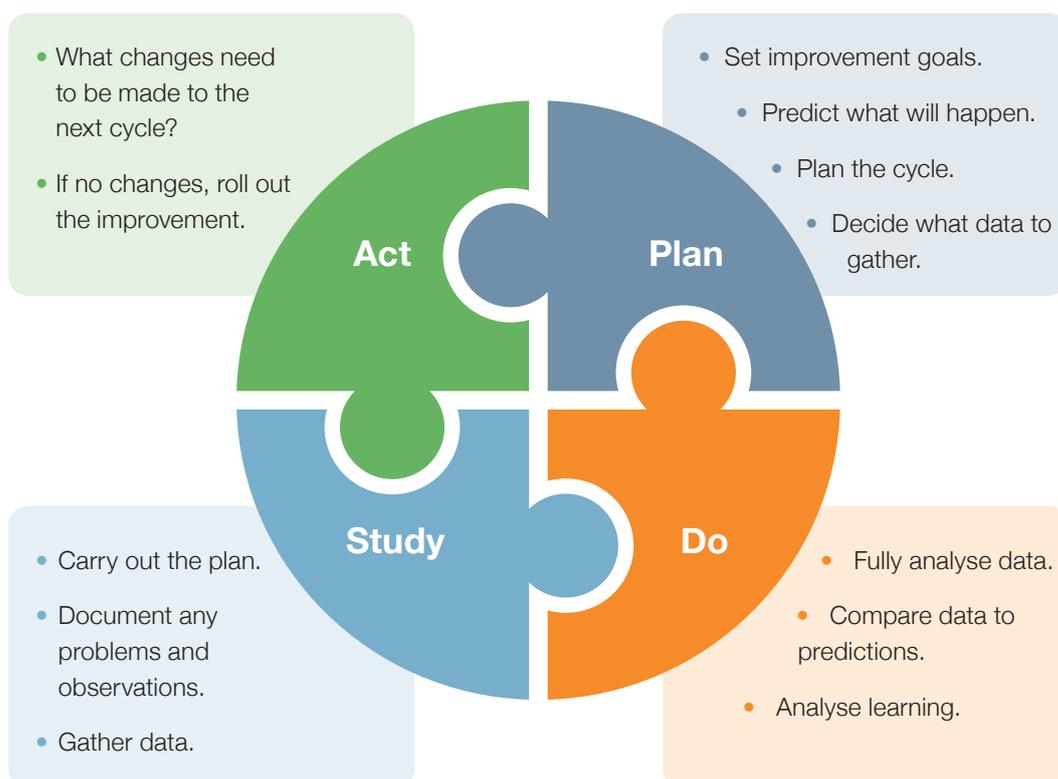
Ensure there is social accountability for NSS services and that participation and monitoring leads to learning and improvement.

There are many policies that place responsibility on the health service to deliver person-centred care, eliminate discrimination and inequity, and to be ultimately accountable to the people receiving services. Partnership working is a fundamental aspect of building social accountability (where citizens hold public servants to account for the services provided), and is rooted in a rights and values-based approach. This places a moral responsibility on services to effectively involve patients and the public in decision making.

Improving access to and use of data is an important element of strengthening transparency and accountability, and in ensuring that the PPP strategy objectives are being achieved. Recent approaches to evaluation of patient and involvement suggest that participatory methods should be used to develop measures and indicators, with representatives playing a key role. Therefore representatives will be included in the design and implementation of any monitoring and evaluation processes for this strategy.

A key component of improving accountability, assurance and learning will be to better utilise patient feedback data for service improvement. It is planned to implement annual patient experience surveys for all programmes. These will be initially piloted with one or two programmes to incorporate any learnings before rolling out across all programmes, using the Plan, Do, Study, Act model (see figure 6).

Figure 6: Plan Do Study Act (PDSA) model for Patient and Public Partnership



Source: HSE Quality Improvement Tools

Summary of actions:

- **Ensure clear governance and accountability structures for PPP**

- Ensure named senior responsible officers across the organisation.
- Ensure public participation on key governance and decision-making groups and that formal assurance processes are in place.
- Regular reporting to the board and other committees.

- **Measure success of PPP**

- Co-develop a suite of person-centred quality indicators and conduct annual patient experience surveys.
- Improve methods of collection utilising digital solutions where possible.
- Continue to improve the presentation and sharing of service performance information.
- Monitor implementation and attainment of PPP strategy objectives.



Appendices

Appendix 1: Workshop Participants

Name	Department
Fiona Treacy	PPP Project Lead
Donna Brady	DiabeticRetinaScreen
Annette Ryan	PPP Representative
Yvonne Cahalane	PPP Representative
Sandra Eaton	NSS Communications
Marianne Murphy	PPP representative
Mary Hayes	PPP Representative
Eileen Woods	PPP Representative
Gerry Clerkin	NSS Quality, Safety and Risk Manager
Cliona Loughnane	PPP Representative
Sonia Maguire	Quality and Safety Support
Zita Flatley	PPP Representative
Carrie Powells	CervicalCheck
Belinda Carroll	PPP Representative
Anne Marie Kiernan	NSS Quality, Safety and Risk Manager
Mary Hewson	PPP Representative
Colette Murphy	DiabeticRetinaScreen
Angela Reilley	PPP Representative
Heather Byrne	BowelScreen
Keith Cairns	PPP representative
Leona Kelly	BreastCheck
Mila Whelan	HSE Quality Improvement Team
Carol Murphy	CervicalCheck
Rosin O'Hara	Health Promotion
Deirdre Ryan	Screening Promotion Manager
Helen Kavanagh	Diabetic Retina Screening

Sara McNally	Programme Evaluation Unit
Grace Rattigan	PPP Representative
Antoinette Morley	Senior Health Promotion Officer
Brigid Doherty	PPP
Breda Duff	PPP Representative
Kevin Murphy	Client Services, NSS
Sarah Kennedy	BreastCheck
Lisa Heffernan	BowelScreen
Liz Cullen	PPP Representative
Frances McNamara	Head of Screening, NSS
Jane Lynch	NSS Head Office
Roisin O'Hara	Screening Promotions
Estelle McLaughlin	Project Management Office
Paul Kearney	QA BreastCheck and BowelScreen
Nick Eichler	Public Health
Caroline Mason-Mohan	Public Health
Nadine Ferris-France	External Facilitator

Appendix 2: Theory of Change for NSS Patient and Public Partnership Strategy



Appendix 3: NSS Patient and Public Partnership Action Plan

Objective	Actions	Resources	Timeline	Lead	Supporting Role	Stakeholders	Success Criteria
1. Empower patients and public to play a meaningful and active role in the NSS							
1.1 Establish an effective and representative panel	<p>a) Analyse barriers to engagement and screening attendance:</p> <ul style="list-style-type: none"> Engage with groups who regularly do not attend for screening. Engage people from marginalised and seldom heard groups 	<ul style="list-style-type: none"> Roadshows Focus Groups Surveys 	Annually	Public Health / PEU	Communications and Health Promotion	GPs Practice Nurses Well Women Clinics Patient Reps Voluntary Sector Advocacy Groups	<ul style="list-style-type: none"> Barriers Report Diverse recruitment campaign Number of respondents from various background(demographic info) Panel of 25-30 members
	<p>b) Develop a targeted engagement strategy which includes marginalised and underrepresented groups:</p> <ul style="list-style-type: none"> Recruitment campaigns Targeted recruitment 	<ul style="list-style-type: none"> Budget for recruitment and advertising Venues 	Recruit annually	PPP Lead	QSRM Health Promotion	Patient reps Advocacy Groups	<ul style="list-style-type: none"> Diverse and representative panel in place (demographic data collected) Number of inductions Attendance rates at meetings
	<p>c) Establish a diverse and representative panel.</p> <ul style="list-style-type: none"> Request commitment of at least 12 months Have meeting quorum with minimum attendance from representative groups Ensure all stakeholders informed of PPP vision. Create induction programme including face-to-face and online options (video talks / presentations) 	<ul style="list-style-type: none"> Training for staff and panel members. Consider incentives e.g. paying people to participate. Induction for panel members. 	Annually	Quality and Risk Lead	PPP Lead	Champions from each programme Finance	<ul style="list-style-type: none"> Patients are involved at all stages and levels of the screening service. Evaluation and feedback forms from panel members

Objective	Actions	Resources	Timeline	Lead	Supporting Role	Stakeholders	Success Criteria
	<p>d) Establish ways of working for the panel (mechanics of how the panel will function)</p> <ul style="list-style-type: none"> Use a range of engagement methods to ensure fairness and maximise involvement e.g. use technology for meeting remotely; hold meetings at weekends; hold regionally. Co-produce terms of reference. Outline roles and responsibilities of panel members. Create an Engagement Toolkit which outlines how to establish: Clarity of purpose; map expectations etc. (see DH Public Involvement Framework). Named contacts for each area of work. Annual workplans Regular PPP workshops (see action 2.3a too) 	<ul style="list-style-type: none"> Staff time Budget Venues 	<p>Start October 2019 - Annually</p>	<p>Quality and Risk Lead</p>	<p>PPP Lead PPP Champions</p>	<ul style="list-style-type: none"> Programme managers Interim Management Team Operations Team 	<ul style="list-style-type: none"> Defined terms of Reference Defined workplans Clear points of contact Production of an annual report outlining what the panel has achieved and what has changed.
	<p>e) Co-develop a shared decision making framework for screening healthcare professionals/ providers and PPP.</p>	<p>N/A</p>	<p>December 2019</p>	<p>Quality and Safety Lead</p>	<p>Public Health PPP Lead</p>	<ul style="list-style-type: none"> PPP Champions Head of Screening Programme Managers 	<ul style="list-style-type: none"> Co-developed framework Feedback and evaluation measures

Objective	Actions	Resources	Timeline	Lead	Supporting Role	Stakeholders	Success Criteria
1.2 Improve Screening Health Literacy of Public and Staff	<p>a) Improved health literacy for staff:</p> <ul style="list-style-type: none"> Ensure clear delivery of key screening messages (including risk and limitations) Support people to make an informed choice. 	<p>Training for healthcare professionals</p> <ul style="list-style-type: none"> Direct from NSS Via training institutions e.g. medical schools, ICGP, radiography training etc. 	Start October 2019 – ongoing	Public Health Programme CAGs	Training coordinators	<ul style="list-style-type: none"> Primary Care Radiographers Health Promotion Colleges 	<ul style="list-style-type: none"> Increased knowledge (pre and post training knowledge rates) Question on annual and staff patient surveys
	<p>b) Use of Plain English and removal of jargon in meetings and in policies/ reports.</p> <p>Provide:</p> <ul style="list-style-type: none"> Training 'Jargon buster' sheets 	Training	October 2019 – ongoing	PPP Lead	PPP Champions	Programme Managers Clinical Leads NALA	<ul style="list-style-type: none"> Increased understanding
	<p>c) Improved population screening health literacy</p> <ul style="list-style-type: none"> Review programme materials and leaflets to include infographics Mass media campaigns Improve access to trusted resources e.g. NSS site Ensure tailored materials that are clear, transparent and accessible to a variety of users e.g. easy read other language. 	<ul style="list-style-type: none"> Financial IT / digital 	October 2019- ongoing (campaign tbc)	Director of Public health	Communications Health Promotion Programme Managers PPP Lead	<ul style="list-style-type: none"> Voluntary Sector Organisations Advocacy Groups Media Outlets 	<ul style="list-style-type: none"> Focus groups Number of people reached Improved uptake (generally and from target groups) Hits on website (or trusted resource) Number of materials in different languages; easy read etc

Objective	Actions	Resources	Timeline	Lead	Supporting Role	Stakeholders	Success Criteria
2. Embed partnership working across the NSS							
2.1 Leadership and buy-in	<p>a)</p> <ul style="list-style-type: none"> Have named senior responsible officers. Provide routine updates at Interim Management Team, Operations Team and management meetings on developments in NSS and programmes. 	N/A	July 2019 - quarterly	National Director	Quality and Risk Lead	Interim Management Team	<ul style="list-style-type: none"> Named leads Reporting Framework Evidence of action
2.2. Culture Change:	<p>a)</p> <ul style="list-style-type: none"> Use a Values in Action type model to create awareness and change: Identify champions at all levels of screening services Develop a poster (job aid; patients stories and theory of change) Regular communication and sharing stories 	Staffing Financial	Immediate start and ongoing process	Project Team	Champions at all levels PPP reps Comms Reps	Interim Management Team	<ul style="list-style-type: none"> PPP representation widely accepted as the norm Named PPP champions per programmes Number of networking events
2.3 Establish a PPP Hub	<p>a)</p> <ul style="list-style-type: none"> Develop an internal communication strategy Regular internal emails (PPP newsletter) Regular briefing sessions CPD sessions Hold regular workshops every 6 months for staff and patients Establish working groups for strategy implementation per workstream 	desk/room Comms IT Financial	Jan 2020 Start Oct 2019	PPP Lead PPP Lead	Facilities <ul style="list-style-type: none"> Communications Public Health 	N/A Programme champions	<ul style="list-style-type: none"> Desk allocated Number of communications Meeting minutes Workshop reports Feedback and evaluation forms CPD points allocated for training

Objective	Actions	Resources	Timeline	Lead	Supporting Role	Stakeholders	Success Criteria
2.4 Incorporate PPP into routine business	a) Incorporate PPP into NSS Policies and Processes Include in: <ul style="list-style-type: none"> • NSS charter • Programme charters • NSS business plan • Programme business plans 	N/A	2020 Reviews and ongoing annually	Chief Executive Officer	Programme Managers	Programme Managers Quality and Risk Manager	<ul style="list-style-type: none"> • PPP evidenced in policies
	b) Training programme <ul style="list-style-type: none"> • Needs analysis: survey staff and PPP reps on training needs • Deliver training programme 	Training budget	Start October 2019- End January 2020	PPP Lead	Chief Executive Officer	HR IT Comms	<ul style="list-style-type: none"> • Results of survey • training programme • Feedback and evaluations from training
	c) Establish ways of working for PPP in routine business	Staff	Ongoing	PPP Lead	Admin support	PPP Champions	<ul style="list-style-type: none"> • Feedback responses from PPP reps on inclusion
	d) Develop tools for PPP: <ul style="list-style-type: none"> • Attitudes checklist • Mapping expectations • Induction protocols • Expenses • Jargon buster 						

Objective	Actions	Resources	Timeline	Lead	Supporting Role	Stakeholders	Success Criteria
3. Strengthen accountability, assurance & learning							
3.1 Accountability	a) Identify who is accountable and what for: <ul style="list-style-type: none"> • Create an organisation chart (for PPP) with responsible persons • Have PPP as a standing agenda item on Interim Management Team meetings 		Monthly	Quality and Risk Lead	PPP Lead		<ul style="list-style-type: none"> • Named accountable persons • PPP as a standing agenda item on various board and committees (to be documented) • Patient reported experience of engagement on meetings
	b) <ul style="list-style-type: none"> • Ensure patient and public representation on key governance groups and ensure there is formal assurance processes 	PPP reps	Start Oct 2019-ongoing	QSRM	PPP Lead	Head of Screening Programme Managers	
3.2 Measuring Success of PPP	a) <ul style="list-style-type: none"> • Co-develop a suite of organisational indicators with targets for PPP and a reporting framework • Incorporate new methods for obtaining feedback (e.g. consider digital tools) 	Analytics	Annually	QSRM	PPP Lead	Interim Management Team	<ul style="list-style-type: none"> • Progress reports to IMT

Objective	Actions	Resources	Timeline	Lead	Supporting Role	Stakeholders	Success Criteria
	<p>Incorporate routine patient feedback and patient experience surveys into annual business and quality improvement</p> <ul style="list-style-type: none"> • Conduct annual patient experience surveys • Staff surveys • Complaints • Ensure learning incorporated into service delivery 	<p>Include in contracts and MOUs</p>	<p>Annually (start pilot programme in 2019/20)</p>	<p>Head of Screening</p>	<ul style="list-style-type: none"> • Quality and Risk Manager • Public Health 	<ul style="list-style-type: none"> • Programme managers • Providers 	<ul style="list-style-type: none"> • Improved patient and staff experience and satisfaction rates • Fewer complaints • Positive media stories • Positive public image
	<p>b)</p> <ul style="list-style-type: none"> • Improve how performance information is presented to the public and PPP reps 	<p>Analytical</p>	<p>Quarterly</p>	<p>Director of Public Health</p>	<p>PEU Analytics</p>	<p>PPP Lead Programmes</p>	<ul style="list-style-type: none"> • Performance reports presented in timely and clear format
<p>3.4 Monitor and evaluate the effectiveness of PPP in NSS Policies</p>	<p>a) Ensure Monitoring & Evaluation of implementation of PPP components in policies (see 2.4)</p>	<p>N/A</p>	<p>Ongoing</p>	<p>National Director</p>	<p>Chief Executive Officer</p>	<p>Interim Management Team</p>	<ul style="list-style-type: none"> • Reports • Implementation Plans • Evaluation findings

Glossary

NCRI	National Cancer Registry of Ireland
NIHS	National Intercultural Health Strategy
NSS	National Screening Service
PPP	Patient and Public Partnership
WHO	World Health Organization

Definitions

Co-develop	To develop something jointly
Co-production	Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation. Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective. (NHS Co-production Model)
Participatory Governance	Participatory governance is embodied in processes that empower citizens to participate in public decision-making, and it has been gaining increasing acceptance as an effective means to tackle 'democracy deficits' and improve public accountability
Patient Engagement	Bringing the perspectives of patients/service users, family members and carers directly into the planning, delivery and evaluation of health care.
Person-centred care	Services that are "respectful and responsive to individual's needs and values and partners with them in designing and delivering that care" (HSE Quality Improvement Framework).
Rights-based approach	A rights-based approach is a conceptual framework for the process of human development that is normatively based on international human rights standards and operationally directed to promoting and protecting human rights. It seeks to analyze inequalities which lie at the heart of development problems and redress discriminatory practices and unjust distributions of power that impede development progress.
Social accountability	Social accountability is defined as an approach toward building accountability that relies on civic engagement, i.e., in which it is ordinary citizens and/or civil society organizations that participate directly or indirectly in exacting accountability
Values-based approach	Developing culture and actions based on a set of core values



An tSeirbhís Náisiúnta Scagthástála
National Screening Service